

From the Chair

It is my great honor to write you as the chairman of the board of CCA. I want to thank the board of directors for electing me in February, and I want to convey to you on behalf of the board our commitment to serving CCA's goals and mission. Let me introduce you to our three newest board members: **Tony Davis**, a dentist in Huntsville, Alabama, **Lynne Marriott**, a writer in Dallas, Texas, and **Sally Longroy**, an attorney in Dallas, Texas.

The most significant item I need to share with you concerns CCA's financial status. To be very candid, we have had a very rough two years. It's been hand-to-mouth at best, and that's the bad news. We are finally somewhat stable due to the generosity of Cher, our honorary chair. Cher has donated a portion of ticket sales from her *Believe* tour! That's the fantastic news. Even more great news is that we have several efforts under way to provide funding for the future. We need help from everyone who feels that CCA provides a valuable service. I've listed a few of those projects and ideas for you here.

First, the "**2 by 2 Challenge**" campaign is just getting under way. "2x2" stands for "Two million dollars raised by the end of 2000." To make this happen, we need to get 2,000 people to commit to raise \$1,000 by the end of 2000. Think about it, how hard would it be to raise \$1,000 over the next year? Please sign up today, and get several of your friends/business associates/ business owners, etc. to join in. Look for more details on pages 4 and 5 of this newsletter.

see **Message from the Chair**, page 7

Ninth Annual Cher's Family Retreat Held in Orlando

Walt Disney World was the site of the 1999 Cher's Family Retreat. Families from California to New Jersey converged on **Disney's Hilton Hotel** for a memorable weekend of fellowship and fun. This retreat was especially noteworthy because the first retreat had been held at Disney World nine years prior.

The retreat began on Thursday evening with registration and the traditional ice cream party which was held poolside. During that time, retreat regulars caught up on each other's lives while families new to the retreat became acquainted. In no time at all, the sounds of play, laughter and friendly chatter could be heard as kids and adults enjoyed swimming and ice cream treats.

Friday morning saw everyone up early and raring to go. **Char Smith** and board member **Diana Sweeney** had set up their makeshift office in the lobby to help fami-



lies make decisions on how to make the most of the three-day visit. Where should we start—the Magic Kingdom, the Animal Kingdom, Epcot Center, or MGM? Right away families partnered up and were off and running in many different directions.

When lunchtime rolled around everyone rushed to the **Rain Forest Café** to meet with CCA's national spokesperson, **Cher**. Retreat-goers were greeted at the restaurant with souvenirs and a feast of hamburgers, pizza, and chicken nuggets shaped as dinosaurs. Cher arrived in Santa-like fashion with bags filled with

see **Cher's Family Retreat**, page 2





Meet 14-year-old 8th grader Cindy DelaRosa

Q. Where were you born?

A. I was born in Houston, Texas, but I live in Janesville, Wisconsin.

Q. What are your hobbies?

A. I like dancing, swimming, biking and playing volleyball.

Q. What other activities do you enjoy?

A. I like going to the movies and having sleep overs with my friends.

Q. What kind of craniofacial condition do you have?

A. I have Cystic Hygroma for which I have had many surgeries.

Q. Have you attended CCA's Annual Family Retreat?

A. Yes. My mother and I have attended five retreats.

Q. What do you like best about them?

A. I like seeing all of the people that come and I like going to a new state each year.

Q. What has growing up with a craniofacial condition taught you ?

A. I have learned more about health care and to accept people for what they are, not what they look like.

Q. What advice can you give younger children who are dealing with craniofacial problems?

A. Don't let anybody tell you, you aren't going to get better and don't let them make fun of you.

Just want to say that I love Children's Craniofacial Association because of all the opportunities they have given me like meeting some great kids that I am now friends with. 😊😊😊

Cher's Family Retreat, cont'd from page 1

hats, T-shirts, teddy bears and more. As is Cher's way, she spent the afternoon chatting with each family and posing for photographs as mementos.

After the last family had enjoyed special time with Cher, she was whisked away to Tampa for yet another venue on her worldwide *Believe* tour that is benefiting CCA.

Friday night activities included a picnic and an anticipated pool party. However, a looming thunderstorm forced the picnic indoors. No one was daunted as each enjoyed hotdogs and lively conversation inside.

Families came out early Saturday morning to enjoy the second day at the various parks. By most accounts, the highlight of the retreat weekend was the much-anticipated Saturday night banquet and dance.

Moms, dads and kids of all ages spent the night rockin' and rollin'. Folks cheered as **Amanda Critchlaw, Renee Dubyk, and Zach Bordonaro** battled to claim the hoola hoop championship. The hokey pokey and the conga were big hits with **Scott Guzzo** leading the conga line. The evening concluded



with everyone being totally frazzled from a night of dancing, food and fun.

Sunday morning brought tearful good-byes and promises to see each other next year. However, several families opted to spend one more day in hopes of prolonging the feeling of "family." As people departed, they couldn't help but reflect on this incredible experience that can only be described as *spiritual*. 😊😊😊



In My Own Words... by Stephen Wright

I am a 30-year-old, who has Crouzon's Syndrome. I have undergone 23 surgeries resulting in a completely reconstructed face. I have had experience with cheek implants, a chin implant, rib grafts and an intensive approach referred to as a Lefort III. My latest surgical venture was in the summer of 1999 when I opted to have my forehead reconstructed utilizing a new technology called "bone source."

The surgeons used 35 grams of a substance known as "bone source" to build up the indented and sloped portions of my forehead giving it a nice rounded appearance. The surgery took approximately three hours and I opted to stay in the hospital overnight. I had not had my forehead reconstructed in the past although I had gone through a Lefort III. In my thinking, it was too severe and dangerous to remove the forehead, reshape it, and then wire it back into place. However, the new bone source allowed for an overlay of the substance in order to build up the needed areas without the need to break bones. The physicians informed me that this new material was reducing the number of rib and hip grafts being used. Speaking from someone who has had ribs harvested for grafts, in my mind, this was a giant step forward!

It has now been ten years since I experienced the Lefort III to correct the Crouzon's Syndrome. Ten years is a long time when considering the rapid advances in medical technology made during that same decade. It is precisely this type of technology that allows additional opportunities and choices for people with craniofacial challenges. As I think back to 1989, a CAT scan took an hour and one

had to lie completely still the entire time. Just this past summer, I underwent a CAT scan in a matter of five minutes.

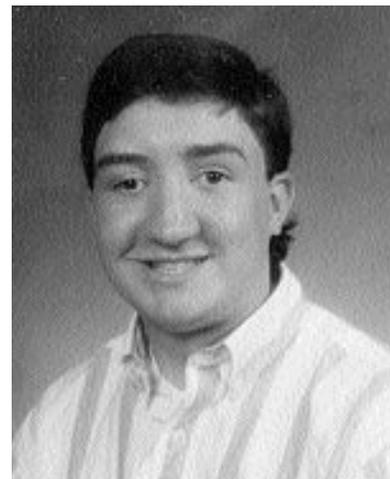
I encourage interested people to discuss bone source with their surgeons to see if this is a viable option.

I also wish to take this opportunity to share with you my involvement with CCA. I first became acquainted with the organization in 1988 through a Dear Abby newspaper article. Soon after that, I was featured in a PARADE magazine article about the Lefort III procedure. Later I had the privilege of producing two more articles for PARADE including an interview with Cher, CCA's national spokesperson, from her Malibu home. My second article was an interview with Dr. Paul Tessier, a pioneering surgeon, at his office in Paris.

It has been quite a challenge to go through the trials of having Crouzon's, but the benefits have outweighed the burdens. I believe that learning to successfully shoulder a heavy burden makes one stronger when meeting other challenges in life. In the long run, the suffering increases both patience and tolerance and allows one to develop compassion for one's fellow man. These qualities, which are not "a given," but rather cultivated traits, take time and a tremendous amount of care.

NOTE from the EDITOR: Although Stephen Wright's experience with bone source was a successful one, the following reservations and explanations should be noted.

Bone source is made of a substance similar to hydroxy appetite, which is coral or essentially a calcium phosphate. It is mixed with water and occasionally other



matter and it acts like clay that can be molded. It does adhere to the bone because the bone can grow around it. However, bone cannot grow into it.

One craniofacial surgeon that I consulted received a supply of the bone source on the very day that the FDA approved it. This physician got a very early experience with utilizing this substance. However, this particular doctor's experience was one of a high rate of infection. Almost half of his patients were experiencing infections. He ceased using the substance at that point. In fact, in a paper delivered at the international meeting of craniofacial surgeons, one physician collected data from a number of surgeons and found the infection rate to be quite significant. Therefore, although some doctors continue to use bone source, others have stopped using it.

FINAL NOTE: Decisions regarding surgery, surgical technologies and surgical supplies are very personal, individual choices involving the patient, his family, and the craniofacial surgeon and team. This article is neither meant to encourage nor discourage the use of particular medical substances or techniques. ☺☺☺

Take the 2x2 Challenge

Children's Craniofacial Association wishes to make the next millennium a better one for children with facial differences and for their families. Therefore, CCA has designated 2000 as "The Year of the Child." As this new year approaches, we are asking you to help us raise \$2,000,000 to fund programs for education, psychosocial service and public awareness, as well as emotional support for our families.

That's the 2x2 Challenge: Raise \$2,000,000 by the time we ring in 2001! We realize that this is a tremendous challenge, but one that we can achieve collectively. This is a goal that can be met in a very personal way. By becoming one of our 2,000 individuals, families, civic groups or corporations nationwide, who commits to raise \$1000 or more, the goal is attainable.

How can you help accomplish this goal?

On the next page we've included a fund-raising idea list to help get you started. Simply pick your favorite method(s) of fund-raising ideas and fill out the regis-

tration card below and mail or fax the completed card to CCA. Upon receipt of the card, CCA will send you details for implementing the event. Recruit your friends, neighbors, coworkers, local organizations, schools, or businesses to help you with your goal.

Exciting Bonus!

In an effort to make the challenge more exciting, we are giving away incentives. These include 2x2 Challenge t-shirts, autographed copies of Cher's book, *The First Time*, autographed copies of Cher's chart-topping CD, *Believe*, and a grand prize of a trip for four to **Walt Disney World**.

Call 800-535-3643 today for additional registration packets to send to friends. Take the 2x2 Challenge! It will be fun and give meaning to your life and the lives of others. But most importantly, your charitable efforts, regardless of the amount, will lift the spirit and self-esteem of a child with a facial difference. We thank you for your consideration and for your assistance. We look forward to announcing the success of this initiative! 🎉🎉🎉

Prizes:

1st Prize: Walt Disney World

To the family/group who raises the most money, a Grand Prize trip for five days and four nights for four (4) to Walt Disney World.

Fly out on American Airlines and stay at the **Hilton in the Walt Disney World Resort**.

Raise \$500 or more:

A CCA 2x2 Challenge T-shirt to everyone who turns in \$500 or more.



Raise \$1000 or more:



An autographed copy of Cher's new book, *The First Time*, plus an autographed copy of her new CD, *Believe* to the first 25 who submit \$1,000 or more.

and much more!

I'd like more information on how to do the following kinds of fund-raising events _____

I have some friends who would also like to take the 2x2 Challenge. Please call me for contact information.

I know of some organizations and associations that could provide support for this worthwhile cause. Please call me for contact information.

I support your cause but am unable to do a fund-raising event. Here is my donation of _____

Charge to my MasterCard VISA Other _____ Expiration Date _____

Name on Card _____ Signature _____

My name is _____

Street Address _____

City _____ State _____ Zip _____

Phone _____ Fax _____ e-mail _____

Fund-raising Ideas

Your hobby, talent or great ideas can be turned into a fund-raiser. Team up with friends or family to have a show, sale or contest. If you like cars, motorcycles, etc. have a show, race or rally. If you like crafting have a show/sale. Everyone has a talent or hobby. Be creative!

- Face-to-face solicitation**—Share CCA's mission with the company you work for and other businesses in your community. Ask for donations or ask them to match funds you raise.
- Friends and family letter**—Send a fund-raising letter to family, friends and associates.
- T-shirt sales**—Take orders for shirts provided by CCA.
- Cash containers**—Place containers provided by CCA in local stores.
- Neighborhood door-to-door walk**—Collect donations in your neighborhood.
- School project**—Organize a fund-raising project for your child's class or school. "Kids Helping Kids"
- Caricatures or pencil sketches**—Take orders and collect photos and CCA will enlist artists to draw caricatures or sketches.
- "Put On A Happy Face" event**—One-day event for families including face painting, balloons, food, games, etc.
- Family Fun Day with Bands**—One-day family event featuring local bands.
- Raffles**—Procure donated prizes from local merchants and sell chances.
- Kitchen Shutdown**—Obtain donations of dinners from seven local restaurants and raffle a week's worth of meals.
- Craft Fair**—Obtain donated space from a school, church, mall or vacant retail space and sell space to local crafters. Sell food, balloons, face painting, etc.
- Car wash**—Ask local merchant to provide space and water.
- Yard Sale**—Ask neighbors, friends and/or family to join in a yard sale.
- Walk-a-thon, Hop-a-thon, Dance Marathon or Hula-Hoop-a-thon**—Organize children, work associates and/or friends and have them take pledges per mile walked.
- Bike-a-thon**—Organize children, work associates and/or friends and have them take pledges per mile ridden.
- Car Rally**—Type out directions for a route using visual icons. Charge entry fees. Have a picnic at the end of the day and present prizes.
- Motorcycle Run**—Ask local Harley Club to hold a fund-raiser for you.
- Dog Show—Horse Show—Car Show**—Collect entry fees. Ask local dog/horse/car club members to judge. It may be that there are shows going on in your area. You could get them to donate proceeds.
- Golf Tournament**—Give a nice donated gift to the closest to the hole at a driving range. Charge a dollar a ball.
- Fishing Derby**—Collect entry fees and give prizes for the most total pounds and largest fish.
- Luncheon/tea/picnic, etc. at your house**—Invite friends to your house and share CCA's mission with them.
- Chili (Tofu, Crawfish, Lobster) cook-off**—Locate an appropriate space and give prizes for the best, most creative, etc.
- Sports tournament**—Softball, volleyball, basketball, golf, tennis—Charge an entry fee, get corporate sponsors, give prizes.

Pick your favorite idea from the list, or select a combination. Mail us the completed registration card and we'll send you the details on how to implement the event. Or, simply use our list to brainstorm your OWN ideas. (If you develop a great idea that's easy to duplicate, send it to us and we'll pass it along to others.)

Cher's *Believe* Tour Benefits Children's Craniofacial Association

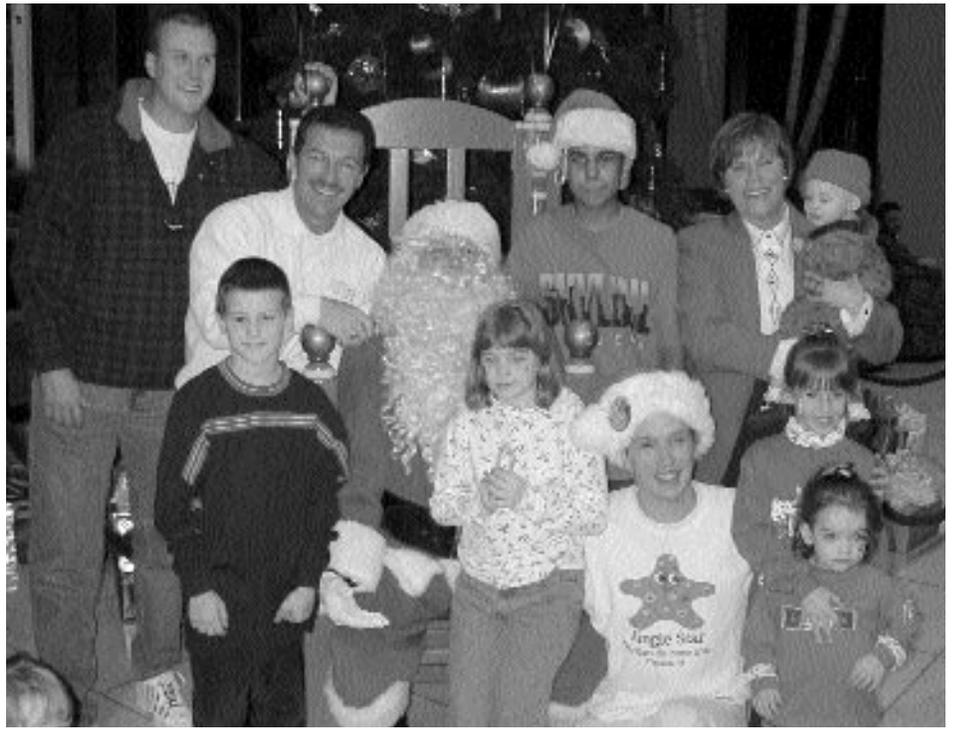
Six months ago Cher launched her first tour in ten years, opening in Las Vegas on June 11, 1999, and announcing that a portion of the proceeds would go to CCA. Cher's high-tech North American extravaganza, *Believe Tour*, was met with much enthusiasm and was followed with a European version. Cher will ring in the millennium with a concert in Atlantic City. And if that isn't enough, she will return to the U.S. and Canadian tour circuit concluding this whirlwind year in March 2000!

Children's Craniofacial Association is so proud of Cher and her artistic accomplishments of the year with her critically acclaimed role as Elsa in *Tea with Mussolini* and her greatest achievement of her 35-year musical career, *Believe*. Our greatest pride comes from knowing that she is CCA's strongest supporter and so lovingly gives of her time, resources, and energy for craniofacial children and their families. We extend our thanks and love to you, Cher! 

1999 Christmas Party

The 10th Annual Holiday Party was held by the Dallas based CCA office on Saturday, December, 11th.

Approximately 350 children, siblings, parents and physicians gathered to celebrate the season. NBC Dallas affiliate news anchor and radio personality **Brad Wright** hosted for the fourth consecutive year. The children made holiday crafts, sang songs and munched on party goodies. The **Dallas Cowboys** sent caps and pennants for the kids. The **Dallas Stars** donated a hockey puck signed by **Brett Hull** and a President's Cup Banner. And, the **Dallas Mavericks** donated tickets to one of their games. Many other door prizes were given out from various Dallas businesses including the **United Artists Theatres, Six Flags Over Texas** and **Six Flags Hurricane Harbor**. Pitcher **Tim Crabtree** from the **Texas Rangers Baseball Team** was on hand to sign autographs and talk baseball. As a highlight, the children had their pictures taken with **Santa Claus**. 🎅🎄



Some kids take time out for a photo with Texas Ranger, Tim Crabtree; TV and Radio personality, Brad Wright; CCA Executive Director, Char Smith; and children's book author, Wayne Smith.



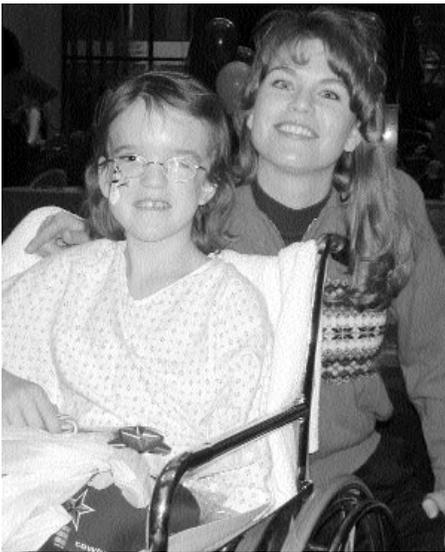
Jim Leonard on the accordion, along with the vocal stylings of Char Smith and Brad Wright lead the party goers in "Jingle Bells."



Cole DuPuis and his mom, Samantha pose with Brad Wright.



Children's book author, Wayne Smith surprised the children with a copy his first book "The Legend of Jingle The Christmas Star" and Jingle the toy star.



Whitney Sisco and Cindy Podner, Nurse Practitioner

Matching Gift

Did you know your personal gift to CCA can be matched with corporate funds if your company has a matching gift program? This means your contribution to CCA can be doubled or even tripled. Please contact your human resources department for information on this program. ☺☺☺

Visit our Web site

www.childrenscraniofacial.com

Children's Craniofacial Association has a new Web address. thanks to **Brenda Molloy** of **MASTERLINK Internet Business Systems**. MASTERLINK, a full-service provider, has designed and is maintaining a home page for CCA. This allows us to describe programs and services, as well as highlight activities and fund-raising efforts. ☺☺☺

Message from the Chair.

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Second, we have received a very generous **matching grant** to hire a **Fund Development Director**. This position is absolutely essential to the long-term viability of CCA. We **MUST** now obtain matching funds of \$25,000 in order to receive this grant. **Can you or your company come to the rescue?** Contact Char Smith at (800) 535-3643 ASAP.

Third, we are experimenting with establishing **State Chapters**. This is an attempt to diversify our fund-raising efforts as well as to become more efficient in our information dissemination.

The **retreat** was a wonderful success in Orlando this year. Forty-six families had a great time at Walt Disney World and the other attractions. Mark your calendar for **June 22-25, 2000** for the retreat in **Denver** this year!

It's too bad my magic wand is in the shop. If it were working, with one wave, I'd be able to assure that CCA would always be financially able to provide the information and services so vital to our craniofacial kids. Until my wand gets fixed, I'm asking all of you to help CCA.

Thank you,
Terry Carmichael, *Board Chair*



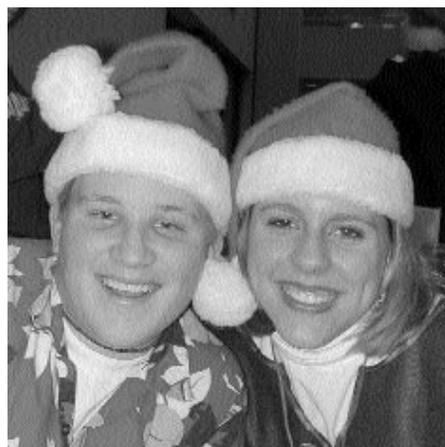
Frosty the Snowman paid us a visit.

Cher's Y2K Family Retreat Scheduled for Denver, Colorado

CCA is solidifying the plans for the 10th anniversary of Cher's Family Retreat to be held in Denver, Colorado at the **Westin Westminster Hotel** on **June 22-25, 2000**.

Melissa Smith, who first became involved with CCA while serving as a regional sales representative for the **Hilton Hotels**, is coordinating this effort. From 1993 through 1998, Melissa was instrumental in negotiating our fabulous

room rates. CCA kids and families hold a special place in their heart for Melissa. She now has her own meeting planning business and is staying involved with us by assisting us not only with the 2000 retreat, but future retreats into the 21st century. We are excited about our partnership with Melissa. Thank you, Melissa, for your dedication! ☺☺☺



A couple of Santa's helpers.

Three Cheers for Volunteers

CCA is so lucky to have a troop of volunteers that ensure our success. The organization has gone through a very critical time in the past several years and the Board of Directors has made very serious decisions concerning the future of CCA. The board is well aware of this most important work and that it is critical to the emotional and physical health of families throughout the country. Therefore, the decision has always been

Informational Booklets to be Updated

Due to the generosity of **CRW Graphics** in New Jersey, Children's Craniofacial Association's booklets for understanding the more common syndrome and craniofacial conditions will be reprinted. Doctors serving on the Medical Advisory Board have been asked to assist in updating the booklets prior to the printing. These booklets are written in an easy-to-read, question and answer format. In addition, it is our hope to add new booklets to the list. 

to seek creative funding possibilities and to ensure that the organization moves forward.

An individual who has been instrumental in keeping CCA going is **Robin Williamson**. Robin's involvement dates back to 1995, serving on the golf tournament committee, then joining the board, and quickly becoming the board Chairperson and serving in that capacity from January 1996 until June 1999. She has always kept the board on track and served on several committees, donating her time and providing her expertise as a creative design professional.

Robin's most recent contribution is the creation of the **2X2 Challenge** fund-raising project. Robin's leadership ensures that CCA thrives and continues with its many essential programs.

Robin is a graphic designer. She lives with her husband, Bruce, and seven-year-old daughter, Miranda, in Carrollton, Texas. Bruce is a graphic designer and illustrator who also volunteers with CCA.

We raise our voices and give three cheers to a super volunteer, Robin Williamson! 

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Cher

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The views and opinions expressed in this newsletter are not necessarily those of CCA.



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